107TH CONGRESS 2D SESSION

S. 969

AN ACT

To establish a Tick-Borne Disorders Advisory Committee, and for other purposes.

- 1 Be it enacted by the Senate and House of Representa-
- 2 tives of the United States of America in Congress assembled,

1 SECTION 1. FINDINGS.

- 2 Congress makes the following findings:
 - (1) Lyme disease is a common but frequently misunderstood illness that, if not caught early and treated properly, can cause serious health problems.
 - (2) Lyme disease is a bacterial infection that is transmitted by a tick bite. Early signs of infection may include a rash and flu-like symptoms such as fever, muscle aches, headaches, and fatigue.
 - (3) Although Lyme disease can be treated with antibiotics if caught early, the disease often goes undetected because it mimics other illnesses or may be misdiagnosed. Untreated, Lyme disease can lead to severe heart, neurological, eye, and joint problems because the bacteria can affect many different organs and organ systems.
 - (4) If an individual with Lyme disease does not receive treatment, such individual can develop severe heart, neurological, eye, and joint problems.
 - (5) Although Lyme disease accounts for 90 percent of all vector-borne infections in the United States, the ticks that spread Lyme disease also spread other disorders, such as ehrlichiosis, babesiosis, and other strains of Borrelia. All of these diseases in 1 patient makes diagnosis and treatment more difficult.

- 1 (6) Although tick-borne disease cases have been 2 reported in 49 States and the District of Columbia, 3 about 90 percent of the 15,000 cases have been reported in the following 10 States: Connecticut, 5 Pennsylvania, New York, New Jersey, Rhode Island, 6 Maryland, Massachusetts, Minnesota, Delaware, and 7 Wisconsin. Studies have shown that the actual num-8 ber of tick-borne disease cases are approximately 10 9 times the amount reported due to poor surveillance 10 of the disease. 11 (7) Persistence of symptomatology in many pa-12 tients without reliable testing makes treatment of 13 patients more difficult. 14 SEC. 2. ESTABLISHMENT OF A TICK-BORNE DISORDERS AD-15 VISORY COMMITTEE. 16 (a) Establishment of Committee.—Not later than 180 days after the date of enactment of this Act, there shall be established an advisory committee to be known as the Tick-Borne Disorders Advisory Committee 19
- 20 (referred to in this Act as the "Committee") organized21 in the Office of the Secretary.
- 22 (b) DUTIES.—The Committee shall advise the Sec-23 retary and Assistant Secretary of Health regarding how

24 to—

1	(1) assure interagency coordination and com-					
2	munication and minimize overlap regarding efforts					
3	to address tick-borne disorders;					
4	(2) identify opportunities to coordinate efforts					
5	with other Federal agencies and private organiza					
6	tions addressing tick-borne disorders; and					
7	(3) develop informed responses to constituency					
8	groups regarding the Department of Health and					
9	Human Services' efforts and progress.					
10	(c) Membership.—					
l 1	(1) Appointed members.—					
12	(A) IN GENERAL.—The Secretary of					
13	Health and Human Services shall appoint vot					
14	ing members to the Committee from among the					
15	following member groups:					
16	(i) Scientific community members.					
17	(ii) Representatives of tick-borne dis-					
18	order voluntary organizations.					
19	(iii) Health care providers.					
20	(iv) Patient representatives who are					
21	individuals who have been diagnosed with					
22	tick-borne illnesses or who have had an im-					
23	mediate family member diagnosed with					
24	such illness.					

1	(v) Representatives of State and local
2	health departments and national organiza-
3	tions who represent State and local health
4	professionals.
5	(B) REQUIREMENT.—The Secretary shall
6	ensure that an equal number of individuals are
7	appointed to the Committee from each of the
8	member groups described in clauses (i) through
9	(v) of subparagraph (A).
10	(2) Ex officio members.—The Committee
11	shall have nonvoting ex officio members determined
12	appropriate by the Secretary.
13	(d) Co-chairpersons.—The Assistant Secretary of
14	Health shall serve as the co-chairperson of the Committee
15	with a public co-chairperson chosen by the members de-
16	scribed under subsection (c). The public co-chairperson
17	shall serve a 2-year term and retain all voting rights.
18	(e) TERM OF APPOINTMENT.—All members shall be
19	appointed to serve on the Committee for 4 year terms.
20	(f) Vacancy.—If there is a vacancy on the Com-
21	mittee, such position shall be filled in the same manner
22	as the original appointment. Any member appointed to fill
23	a vacancy for an unexpired term shall be appointed for

the remainder of that term. Members may serve after the

1	expiration of their terms until their successors have taken					
2	office.					
3	(g) Meetings.—The Committee shall hold public					
4	meetings, except as otherwise determined by the Sec-					
5	retary, giving notice to the public of such, and meet at					
6	b least twice a year with additional meetings subject to the					
7	call of the co-chairpersons. Agenda items can be added					
8	at the request of the Committee members, as well as the					
9	co-chairpersons. Meetings shall be conducted, and records					
10	of the proceedings kept as required by applicable laws and					
11	Departmental regulations.					
12	(h) Reports.—					
13	(1) In general.—Not later than 24 months					
14	after the date of enactment of this Act, and annually					
15	thereafter, the Secretary shall submit to Congress a					
16	report on the activities carried out under this Act.					
17	(2) Content.—Such reports shall describe—					
18	(A) progress in the development of accu-					
19	rate diagnostic tools that are more useful in the					
20	clinical setting; and					
21	(B) the promotion of public awareness and					
22	physician education initiatives to improve the					
23	knowledge of health care providers and the pub-					
24	lic regarding clinical and surveillance practices					

- for Lyme disease and other tick-borne dis-
- 2 orders.
- 3 (i) AUTHORIZATION OF APPROPRIATIONS.—There is
- 4 authorized to be appropriated to carry out this Act,
- 5 \$250,000 for each of fiscal years 2003 and 2004.
- 6 Amounts appropriated under this subsection shall be used
- 7 for the expenses and per diem costs incurred by the Com-
- 8 mittee under this section in accordance with the Federal
- 9 Advisory Committee Act (5 U.S.C. App.), except that no
- 10 voting member of the Committee shall be a permanent sal-
- 11 aried employee.

12 SEC. 3. AUTHORIZATION FOR RESEARCH FUNDING.

- There are authorized to be appropriated \$10,000,000
- 14 for each of fiscal years 2003 through 2007 to provide for
- 15 research and educational activities concerning Lyme dis-
- 16 ease and other tick-borne disorders, and to carry out ef-
- 17 forts to prevent Lyme disease and other tick-borne dis-
- 18 orders.

19 **SEC. 4. GOALS.**

- It is the sense of the Senate that, in carrying out
- 21 this Act, the Secretary of Health and Human Services (re-
- 22 ferred to in this section as the "Secretary"), acting as ap-
- 23 propriate in consultation with the Director of the Centers
- 24 for Disease Control and Prevention, the Director of the

- 1 National Institutes of Health, the Committee, and other
- 2 agencies, should consider carrying out the following:
- 3 (1) FIVE-YEAR PLAN.—It is the sense of the Senate that the Secretary should consider the estab-5 lishment of a plan that, for the five fiscal years fol-6 lowing the date of the enactment of this Act, pro-7 vides for the activities to be carried out during such 8 fiscal years toward achieving the goals under para-9 graphs (2) through (4). The plan should, as appro-10 priate to such goals, provide for the coordination of 11 programs and activities regarding Lyme disease and 12 other tick-borne disorders that are conducted or sup-13 ported by the Federal Government.
 - (2) First goal: Diagnostic test.—The goal described in this paragraph is to develop a diagnostic test for Lyme disease and other tick-borne disorders for use in clinical testing.
 - (3) SECOND GOAL: SURVEILLANCE AND REPORTING OF LYME DISEASE AND OTHER TICKBORNE DISORDERS.—The goal described in this
 paragraph is to accurately determine the prevalence
 of Lyme disease and other tick-borne disorders in
 the United States.
- 24 (4) Third goal: prevention of lyme dis-25 Ease and other tick-borne disorders.—The

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1	goal described in this paragraph is to develop the ca-					
2	pabilities at the Department of Health and Human					
3	Services to design and implement improved strate-					
4	gies for the prevention and control of Lyme disease					
5	and other tick-borne diseases. Such diseases may in-					
5	clude Masters' disease, ehrlichiosis, babesiosis, other					
7	bacterial, viral and rickettsial diseases such as tula-					
3	remia, tick-borne encephalitis, Rocky Mountain					
9	Spotted Fever, and bartonella, respectively.					
	Passed the Senate October 17, 2002.					
	Attest:					

Secretary.

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